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ABSTRACT

This report discusses family policy issues raised by the implementation of Public Law 99-457, Part H, the Infants and Toddlers section of the Education of the Handicapped Amendments of 1986. The report is the outcome of a policy options work conference in which a small group of knowledgeable parents and professionals identified key policy issues. The three issues selected as most important by the group are discussed. These issues are: (1) the definition of services to which children and families are entitled; (2) the role of the case manager; and (3) the identification of family strengths and needs. Policy options available to deal with each issue are outlined, along with the positive and negative consequences of each option. Includes 10 references. (JDD)

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Carolina Institute for Child and Family Policy

THE GENERATION OF POLICY OPTIONS: THE FAMILY

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JUNE 1989

PLEASE FEEL FREE TO COPY ALL OR PARTS OF THIS REPORT AND DISTRIBUTE AS YOU THINK APPROPRIATE.

This publication is the result of a small work conference of parents and professionals who met together to discuss the policy issues involving the role of the family that has been raised by the the implementation of P.L. 99-457, Part H, the Infants and Toddlers section of the Education of the Handicapped Amendments of 1986. The Carolina Policies Studies Program (CPSP) has been funded to track the implementation of this law and to discover factors which allow the law to be successfully implemented. One of the major areas of study by the CPSP is the development of policy options around the topic of family policy.

This law requires the establishment of policies for an Individualized Family Service Plan, stresses family involvement in their child's program, and family empowerment, all of which creates many interesting policy issues to be resolved by the states.

The passage of PL 99-457, Part H, provided the opportunity for states to design and plan for the delivery of appropriate services to infants and toddlers with handicapping conditions and to their families (Trohanis, 1989). It also created a major problem in policy development for state decision makers such as lead agency personnel and the members of the Interagency Coordinating Council. These decision makers were confronted with many decisions regarding the specific policies needed to implement this landmark legislation (Gallagher, Trohanis, & Clifford, 1989).

Policy, in this instance, refers to the rules and standards that are established in order to allocate public resources to meet a particular social need. The written policies should help us understand:

Who shall receive the services?

Who shall deliver the services?

What the nature of the resources are that are to be delivered?

Under what conditions will the services be provided?

These are the questions that will have to be resolved before this law is fully implemented.

Policy Options Work Conferences

One of the problems in generating policy options is that there are few systematic procedures to look at a full range of options, or to consider the often unanticipated consequences of a new policy option (Campbell & Mazzoni, 1977; Steiner, 1981). Governmental decisions are often made under severe time pressures, and predigested solutions are often presented, so that a full consideration of alternatives is never achieved (Wildavsky, 1979). The Carolina Policy Studies Program (CPSP) has been developing a procedure that might allow for a more systematic way of considering available policy options, a policy options work conference. This approach is built upon the model of policy development developed by Gallagher (1981) and is a variation of the "focus group" approach (Morgan & Spanish, 1984; Finn, 1982). It was first piloted in a summer workshop at the University of North Carolina in June 1988.

This small group process brings together 12-15 persons who are knowledgeable about the issues at hand but who come from differing perspectives and responsibilities. Parents, college professors, agency personnel, policy analysts, service providers can

all have an opportunity to contribute to these discussions. Six steps are completed in this process, as follows:

1. **Identification of Key Policy Issues**. The group is asked to brainstorm all of the major policy issues that remain to be solved in a given topic area (e.g. eligibility, finance, etc.). The leader places these ideas on a chart or blackboard. The group is then asked to vote upon the three most significant issues and these then become the focus for the rest of the work conference.
2. **Identification of Policy Options**. Each of the three issues are then addressed, in turn, and the group is asked to provide the variety of policy options that they believe should be considered in coping with each issue. This generally results in seven or eight options per issue for further consideration. Sometimes, a consolidation of options may be considered before going on to the next step.
3. **Consequences of Policy Options**. For each of the options that are under consideration the group is then encouraged to present the various positive consequences (e.g. more children will be served, interagency coordination will be enhanced, etc.) and negative consequences (cost would be too great, not enough trained personnel to carry out option, etc.). For each option then there is developed a range of potential consequences.

4. **Policy Issue Map**. The resulting information then provides a full range of policy options and their consequences for each of the key policy issues identified by the group.
5. **Group Review**. The members of the group are then sent a copy of the draft report for their comments, additions, and deletions.
6. **Product Dissemination**. The resulting manuscript is shared with the ICC chairs, Part H coordinators, NEC*TAS, and OSEP for their review.

Family Policy

One of the clearest priorities of PL 99-457 has been the desire to strengthen and empower the family. Robert Silverstein, Chief Counsel of the Subcommittee on the Handicapped of the Senate Committee, commented upon congressional intent as follows; (Project Zero to Three, 1989):

> Congress wanted the language of the bill to reflect our utmost respect for the family. The word 'family' must appear ten or fifteen times throughout the legislation. This was intentional. Congress was trying to say....Respect the Family.

It is up to the states to determine how to implement the procedures for the Individual Family Service Plan (IFSP) called for in the legislation. Such family policies have to be established by the lead agency and Interagency Coordinating Council in a number of sensitive areas including confidentiality, due process, family assessment, etc. A previous report from the Carolina Policy

Studies Program (Place, Gallagher, & Harbin, 1989) has already indicated that the states are moving slowly on this delicate set of topics.

The Participants

Because of its importance the family policy area was chosen as one of the topics for the policy options work conferences. In order to include a sufficient number of active parents in the work conference, CPSP arranged to have the work conference coincide with the TAPP (Technical Assistance for Parent Programs) conference in Washington, DC in March, 1989. Parents who were especially interested in participating in the policy option work conference were asked to volunteer, as were members of a Family Advisory Group of CPSP. Additional professionals interested in family issues were also invited. The final roster of the participants can be seen in Table 1.

Procedure.

The group began their work with a discussion about the meaning of policy as the rules and standards by which societal resources are allocated, as stated earlier. The working group then identified ten issues of concern in the area of family policy in PL 99-457. (See Table 2) Three major issues were then chosen from this list by majority vote for further elaboration. These issues were (1) the definition of services to which children and families are entitled, (2) the role of the case manager, and (3) the identification of family strengths and needs. For each issue a general interchange of views was held by the group before moving

to options and consequences to make sure that the issue was fully understood by all the group members..

TABLE 1

FAMILY FOCUS GROUP PARTICIPANTS

PARENTS

Maria Anderson
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Minneapolis, MN

Carol Blades
Special Education
Action Committee
Mobile, AL

Phil Davis
Nevada Association
for the Handicapped
Reno, NC

Mary Ann Eaton
Parent Education Project
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Federation for Children with
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Judie Walker
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TABLE 1 (CONT'D)

FAMILY FOCUS GROUP PARTICIPANTS

STATE ORGANIZATION REPRESENTATIVES

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Roxanne Rice
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Washington, DC

POLICY ISSUE #1--PL 99-457. WHAT SERVICES ARE CHILDREN AND FAMILIES ENTITLED TO IN THIS LEGISLATION, AND FROM WHOM?

A wide array of possible services are noted in the law to meet the child's development needs. However, the working group's concern centered around the extent to which these services will be available to the family. Some representative comments during the initial discussion were:

Discussion

- Are all services available to "at risk" kids also?
- When should services begin, before the IFSP?
- Are we creating unrealistic expectations in terms of available services?
- Are we only dealing with services that already exist?
- Is this an entitlement program? Does everyone get needed services regardless of cost or financial availability?
- Will the costs of transportation be covered?
- How closely should the family services be linked to the child's problem?
- Will there be be a "means" test for families?
- What will happen to family services during the transition period at age three?

As can be seen, there was considerable controversy in the group as to where the boundary line for acceptable services should be placed and that difficulty was revealed again in the next step -

the statement of Policy Options. The following six options were presented in group discussion as potential policies to answer the question, What services are children and families entitled to?

POLICY OPTIONS - WHAT SERVICES ARE CHILDREN AND FAMILIES ENTITLED TO?

Option 1 - The services delivered will be predominantly those that are currently available.

Option 2 - All needed family services be delivered.

Option 3 - Child-linked services will be provided and other services may be arranged through case manager, etc.

Option 4 - Only Child-linked services will be provided.

Option 5 - Additional family services beyond child-linked services would be provided when there is a threat of family dissolution.

Option 6 - Other funds will be needed to pay for many family services PL 99-457 will be seen as only the payor of last resort.

The following represent the options and their consequences as viewed by the group. Each option was taken in turn and all major consequences were recorded. The particular options chosen and consequences perceived are obviously a function of the composition of the work group. Different groups might generate different options and consequences. We believe, however, that the general consensus across groups would be quite high.

OPTION #1 - ONLY CURRENTLY AVAILABLE SERVICES WILL BE PROVIDED.

Positive consequences

This may be the best alternative that can be adopted in conservative states. Any other plan requiring new funding might be turned down.

It is the best guarantee that something, some level of services, will be delivered.

Interagency coordination will not be strained since there is little to fight over. it is financially feasible, predictable, manageable.

Professionals will refer families because they know about existing services.

Negative Consequences.

This will continue to foster a fragmented and uncoordinated service delivery system.

Some families with serious needs will not have them met if only current services are available.

State service systems may be frozen at an inadequate level and there would be the illusion that things are OK.

There might be a tendency to avoid examining creative alternatives.

OPTION #2 - ALL NEEDED SERVICES WILL BE PROVIDED TO CHILD AND FAMILY WITH STATE SUPPORT.

Positive Consequences

This would force states to have a clear definition of the range of services available.

This would force states to examine how to broaden options and expand services.

Would allow families to define services desired and mode of individual service delivery.

Negative Consequences

This would be enormously expensive as a total state responsibility.

States might decide to stop participating in the program.

Would eliminate the incentives for parents and professionals to seek additional resources through other programs, if Part H pays for everything.

Professionals might skimp on IFSP to avoid costs.

The limits of service provision might be unclear to service providers.

OPTION #3-FAMILY GETS CHILD LINKED SERVICES-CASE MANAGER MAY SEEK ADDITIONAL HELP THROUGH OTHER PROGRAMS

Positive Consequences

This option would be responsive to family needs without tremendous financial cost to program.

There could be a true identification of needs and the family would likely get needed services.

Professionals would be be more comfortable about placing these needs in IFSP since they wouldn't overload the system.

Would encourage family/professional collaboration.

Family would be more straightforward in identification of needs which would be linked to the child.

This option would reduce the need to retrain professionals for multiple service delivery.

Negative Consequences

Definition and limitation of child-linked services difficult.

Promotes assumption that the needed services are, in fact, out there and all one has to do is find them.

Extra demands on the case manger to find other resources.

OPTION #4 - FAMILY SERVICES LIMITED TO CHILD-LINKED PROBLEMS

Positive Consequences

- Financially more feasible and seems to fit into the law's intent.
- Should reduce the fears of families about professional intervention in family affairs or secrets.
- It would limit the scope of having to identify family needs.
- Easier to demonstrate progress on child goals.
- Would encourage definition of child/linked services, and make it easier to sort out deliverable services.

Negative Consequences

- It would lead to professionally driven, not family driven, plans.
- There would be difficulty in distinguishing child/linked and family related problems.
- Might be used to limit the services provided.
- Separates the child's problem from the overall family situation.
- Makes the program more treatment than support oriented.

OPTION #5-ADDITIONAL FAMILY SERVICES PROVIDED, IF NEEDED TO COUNTERACT THREAT TO THE INTEGRITY OF THE FAMILY ITSELF.

Positive Consequences

- Could focus expenditures on serious family issues.

Might energize social services to work with family.

Conservative political figures might buy into the "Save the Family" approach and support the legislation.

Would appear on the IFSP as a major objective.

Would force a definition of "family" in order to evaluate the threat.

Negative Consequences

It might lead us back to the pathological model by focusing on family problems rather than family resources.

Would discourage coordination if we assume that Part H will do it all alone.

Definition of "family threatening" situations would be difficult.

Would result in greater intrusiveness in the family.

Multiproblem families are difficult to serve and very expensive.

You may put limited resources into areas of tremendous need without the hope of much return.

The family must appear negative to get services!

OPTION #6-PL 99-457 WILL BE SEEN AS ONLY THE PAYOR OF LAST RESORT AND OTHER FUNDS WILL BE NEEDED TO PAY FOR MANY FAMILY SERVICES.

A lengthy discussion ensued at this point regarding finance issues that there was not time to address fully:

1. Entitlement - free services through 99-457 or other sources?

2. Financial mix; family vs. agency as payor.

3, Sliding fee; the consequence of the fee may be to avoid early intervention.

4. Need to clarify entitlement for re-authorization.

This discussion was seen as relevant to family policy but there was not time to deal with these issues. Therefore, consequences were not generated for Option #6. CPSP plans to hold a policy option group conference centered around finance issues and these topics will probably emerge again.

The group showed considerable sensitivity to the issue of program coordination (i.e. if this law takes care of everything then what need is there for coordination?) They also showed a lively concern for whether a concentration on child services would put the program back into a familiar professional-client mold and weaken the family role. There were many tradeoffs and compromises recognized here.

POLICY ISSUE #2-WHO DETERMINES THE RULES ABOUT THE ROLE OF CASE MANAGER IN THE EXECUTION OF THE IFSP?

The law mentions that case management services would be available to help carry out the IFSP and that a case manager from the profession "most immediately relevant" would be named who would be responsible for the implementation of the plan and the coordination with other agencies and persons.

This leaves a great deal of leeway to the states in terms of specifying the detail or the operation of the role; and how it relates to the family. That is what is addressed by the group here.

Discussion

Would parents the able to be reimbursed for this role?

Is another option that parents have the right to veto or reject the case manager? Could family choose case manager?

Other programs have instituted case manager procedures and we should learn from them.

There may be different levels of case management, multitiered roles with different responsibilities for different levels.

A major issue is the training of case managers. The Parent Training and Information Centers have beer. doing this.

The case manager is the one responsible-the buck stops here.

What is the "most immediately relevant" profession?

The ultimate authority of the case manager is to bring about program coordination in a particular case.

Will there be a conflict of interest between the home agency of the case manager and the interest of the client family?

We need a model to evaluate the accountability and monitoring of the case manager? Who will do that?

Involve and coordinate existing case managers.

The Role of the Case Manager

The group spent some time discussing the role and needed skills of the case manager. The case manager is responsible for a "good faith effort" to provide the services that the family requests. This requires that the case manager know service delivery systems, appeal procedures, and how to get services from various authorities. The outcome of the case manager's work should be (1) empowerment of families (2) delivery of services and (3) an evaluation of results, particularly family satisfaction with the program.

Skills needed by the Case Manager

Team building skills.

Teaching parents how to seek services

How to be a confidant to the family

How to monitor and evaluate the services delivered.

Managing the service delivery from the IFSP.

Planning for the transition at age 3.

How to link and access services.

How to advocate for nonexistent services.

How to use and inform Information and Referral systems.

POLICY/OPTIONS-WHO DETERMINES THE RULES ABOUT THE ROLE OF CASE MANAGER?

The following five options represented the group's judgment on the reasonable options available.

1. State, with consumer participation, will define the functions, competencies and roles of the case manager.

2. State will identify the particular professions or agencies who will play the role of case manager.

3. State, will establish range and limits of authority to manage coordination and provide sanctions for noncompliance..

4. States with consumer input, will develop rules for mediating interagency conflicts.

5 Local community will determine the case management services and model to be used.

OPTION #1-CASE MANAGER-STATE WILL DEFINE CASE MANAGEMENT ROLE

Positive Consequences

There would be policy consistency across the state.

The state will become more invested in the program.

It might be possible to initiate a statewide training program under the personnel preparation requirement.

(State, as referred to here, means the lead agency and relevant groups, the central authority in the administration).

Negative Consequences

Such a plan may not meet the diverse needs of communities within the state.

May end up being too restrictive in prescribing one model for the case manager.

Could be stated in such a way as to be unresponsive to the family's needs.

OPTION #2-CASE MANAGER-STATE WILL DETERMINE THE PROFESSIONS AND AGENCIES THAT WILL FURNISH THE APPROVED CASE MANAGERS.

Positive Consequences

It would establish a known cost estimate and number of personnel availability of case managers, since this information, by discipline, is reasonably well known.

It would likely result in more consistency across cases and allow for greater state monitoring and training possibilities.

Negative Consequences

It would almost surely alienate certain professional groups who were not chosen for this role.

It would be likely to result in a political battle for power by various professional groups.

The system could be inequitable for families (what happens if that designated profession has no representatives locally?)

OPTION #3-CASE MANAGER-STATE WILL DETERMINE RANGE AND LIMITS OF AUTHORITY.

Positive Consequences

This responsibility would encourage interagency agreement on setting limits of authority.

Would be likely to require greater state involvement.

Family might be more likely to get services since the case manager would have some tangible influence on service availability.

Negative Consequences

It would be difficult to implement sanctions. Penalties for noncompliance against fellow professionals would be hard to carry out.

Who would be responsible for writing rules setting the limits of authority?

Professional groups may well react, "Who are you to tell us how to do our professional work?"

OPTION #4-CASE MANAGER-STATE WILL PRODUCE RULES MEDIATING INTERAGENCY CONFLICTS WITH CASE MANAGER ROLE.

Policy Consequences

There are currently no mechanisms to deal with such conflicts and this would be one mechanism for conflict resolution.

The lead agency currently has responsibility without authority. This would help them carry out their role.

This would necessarily include the Protection and Advocacy systems and consumers in the development of the mechanisms for dispute resolution.

POLICY ISSUE #3-WHAT POLICIES SHOULD BE ESTABLISHED RELATED TO THE IDENTIFICATION OF FAMILY STRENGTHS AND NEEDS?

This policy issue emerges from the provision in PL 99-457, Part H, for the individualized family service plan (IFSP). One of the IFSP components that the law mandates is:

> A statement of the family's strengths and needs related to enhancing the development of the family's handicapped infant or toddler.

Later on in the law there are other provisions under procedural safeguards which affect the family and present this policy issue. Some of the family's rights are:

> The right to confidentiality of personally identifiable information.
>
> The opportunity for parents and a guardian to examine records relating to assessment, screening, eligibility determinations, and the development and implementation of the individual family service plan.

DISCUSSION

The issue is one of limiting intrusiveness into the family. The term "assessment" itself is a leftover from the days when there was a diagnostic-prescriptive model of treatment. It is not appropriate under a model of family empowerment.

There should be self-identification of problems by the family. What is the real purpose of assessment--are we assessing situations or people?

There is a potentially enormous array of needs to pursue under this mandate.

What is most important is a trust relationship between the professional and family. That must be established before identifying strengths or needs and before intervention.

When we catalogue strengths and needs they must be directly related to the proposed change or treatment.

POLICY OPTIONS-FAMILY STRENGTHS AND NEEDS

1. Local communities will develop policies for the procedures to be followed in assessing family strengths and needs.

2. State will develop a statement of competencies that professionals should have to assess families.

3. State, with consumer participation, will develop the philosophy and guidelines for family assessment.

4. State, with consumer participation, outline specific procedures to be followed in assessment.

5. States will accept professional association standards on family interactions, confidentiality, assessment, etc.

6. There should be state/local interaction in policy development with state policy formed through multiple local policy group formulations.

OPTION #1-FAMILY STRENGTHS AND NEEDS-LOCAL COMMUNITIES WILL DEVELOP GUIDELINES FOR ASSESSMENT OF STRENGTHS AND NEEDS.

Positive Consequences

A diversity of local situations would make local decision making appropriate.

This option would create a feeling of local ownership and would be more likely to meet local needs.

Would encourage creativity and experimentation in service delivery and design.

It would be politically expedient for the state to hand over this task to the local communities.

Negative Consequences

It would be harder to develop a consistent personnel preparation strategy for upgrading professionals on this issue.

There would be a need to clarify what "local" means in this context. There are many overlapping jurisdictions in the various professional programs and groups.

It would be more likely that the old system of diagnosis/treatment would prevail since parent empowerment may not be established locally yet.

There would have to be substantial technical assistance and support to local service providers in order for this to succeed.

Monitoring of the provision would be more difficult.

Local philosophy of treatment may not match the intent of the law.

OPTION #2-FAMILY STRENGTHS AND NEEDS-STATE WOULD DEVELOP PROFESSIONAL COMPETENCIES FOR ASSESSMENT.

Positive Consequences

This would make the expectations for the assessment process clear to all.

There would be consistent procedures for personnel upgrading across the state.

Would tend to promote quality assurance.

Negative Consequences

Might start a major conflict with professional associations who have their own standards for professional assessment.

many working professionals will not meet the standards required.

It will take time to implement such standards and what do we do in the meantime?

OPTION #3-FAMILIES STRENGTHS AND NEEDS-STATE WILL DEVELOP PHILOSOPHY AND GUIDELINES FOR ASSESSMENT.

Positive Consequences

Option would be more likely to encourage shift from old diagnostic/prescriptive approach to family focus.

Basic philosophy of assessment would be consistent across communities.

Local communities would be more comfortable with the state making the rules, if they receive guidance and technical assistance in carrying out the rules.

There could be a state-wide personnel preparation strategy.

A statewide policy would be more likely to influence related policies such as personnel preparation.

Negative Consequences

We may inadvertently disallow some local practices that work.

A general set of rules might not fit local traditions or needs.

Unless mandated, this would be a difficult provision to fund in the implementation stage.

Existing professional practice would have to change and this will likely result in some resistance to the plan.

OPTION #4-FAMILY STRENGTHS AND NEEDS-STATE WILL PRODUCE DETAILED PROCEDURES FOR CARRYING OUT ASSESSMENT.

Positive Consequences

This will result in some procedural commonalties across agencies.

Would encourage the flow of information, especially if the results are computerized.

Would force state policy makers to face up to the issues involved.

Negative Consequences

Specific procedures could run into professional resistance.

There would be many time lags and delays in implementing such a policy.

A restrictive policy may make it difficulty to meet the needs of the certain families.

Restrictive policy would make professional communication difficult.

OPTION #5-FAMILY STRENGTHS AND NEEDS-STATE WILL ACCEPT STANDARDS OF PROFESSIONAL ASSOCIATIONS ON ASSESSMENT, ETC.

Positive Consequences

Many of these proposed standards are already in existence in professional association guidelines.

There would be consistency across states, if national professional standards were accepted.

It would be easier to get standards incorporated into training programs.

Negative Consequences

Who would decide which professional association guidelines would be accepted?

Professional associations often have their own agenda whose first rule is the protection of that particular profession.

How would one enforce such standards across professional disciplines that do not have such standards?

Such standards might restrict state policy too much.

OPTION #6-FAMILY STRENGTHS AND NEEDS-STATE/LOCAL INTERACTION IN POLICY DEVELOPMENT

Positive Consequences

Can encourage a partnership with local policy development personnel.

Interagency Coordinating Council could serve as coordinator for this approach.

Broader based sense of participation and ownership in the eventual policy.

Negative Consequences

This would be a much more complex process requiring a much longer time for development.

If particular community's contribution were not used, the state could lose support of that community.

Final Thoughts

Several general comments should be made about the three issues discussed. There appear to be classic pulls between centering the decision making authority at the state level, or at the local level. The state level provides the opportunity for policy consistency across communities whereas local control may allow for consideration to be given to diversity in the communities. There are pluses and minuses present regardless of the choice made so the consequences of a particular decision are never without some pain.

Another area of general conflict is the advantage and disadvantage of using professional association standards. The involvement of professional associations provides the opportunity to use the best of professional expertise to determine policy but at the risk of being unduly influenced by the self interests of those particular professions. This is another example of the ambivalent nature of many options.

Some of the options considered by the group in this and other policy option conferences seem to clearly conflict with the intent or the letter of the law. No attempt was made to limit the group on that count since laws, regulations, guidelines, etc. can be changed,

and we wished to gain the maximum insight from the group's thinking.

These issues, options and consequences presented here are only a small set of the policy issues involving families, but this approach represents a strategy by which other issues can be elaborated and, through that elaboration, make decision making more systematic and effective.

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